Who's In and Who's Out: Use of Primary Medical Care Among People Living With HIV

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Objectives. We sought to achieve a more comprehensive picture of access to medical care for the treatment of HIV (HIV primary care) by combining evidence of medical services used (health utilization) and epidemiological client-level data.

Methods. This study integrated health information from several data sources to measure utilization of HIV primary care in the St Louis, Mo, area between 1998 and 2002. Data from disparate HIV health utilization databases were combined with data from the Missouri HIV and AIDS Reporting System database and then deidentified to measure client-level utilization of HIV primary care over time.

Results. About half of those with HIV showed evidence of having utilized HIV primary care in a given year. Although most of this group utilized HIV primary care in the first year after they received their HIV diagnosis, evidence of subsequent utilization was inconsistent. Utilization of primary care was most strongly associated with an AIDS diagnosis. About one quarter of people diagnosed with HIV after 1997 had an AIDS diagnosis when they first tested positive for HIV.

Conclusions. This study was the first of its kind to integrate several databases to understand HIV primary health care utilization over a period of years. Our findings reinforce the importance of CD4 and viral load values as indicators of utilization of HIV primary health care, particularly in the absence of other health data sets. The lack of available data and the way in which source data were available limited the study. (*Am J Public Health.* 2007;97:744–749. doi:10.2105/AJPH.2006.090654)

Since the implementation of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in 1990, communities have tried to gain a comprehensive picture of medical utilization for the treatment of HIV (HIV primary care) with incomplete, separately held, and often summarized information. Communities receiving federal funding through the Ryan White CARE Act must assess HIV primary care utilization by persons living with HIV in their jurisdiction. Current regulation requires a seemingly never-ending array of incompatible data for this analysis. Often, some data report client-level health care utilization while other data report utilization by groups or subpopulations, rendering the data incomparable.[1,2] There have been recent attempts, funded by the US Health Resources and Services Administration, the agency that administers funding from the Ryan White CARE Act, to estimate the unmet need for HIV primary care through a comparison of epidemiological data and service utilization data.[2–6] Of this recent generation of studies, 2 studies, conducted in Louisiana and Georgia, used client-level data to understand utilization of HIV primary care.[4]

The Louisiana study relied on mandatory lab-based reporting to estimate unmet need for HIV primary care services in 2002 and found that 45% of those reported as living with HIV disease did not receive a viral load or CD4 test during the 2002 period. The authors also found that the proportion of people in care varied considerably by geographic region. The findings were considered conservative because laboratory reporting was not 100% complete, the use of HIV and AIDS Reporting System (HARS) data was inflated (because the system does not track movement out of the state [migration]), and HIV primary care utilization data were not used as another indicator for HIV primary care access.[4]

The Atlanta study attempted to combine several care data sets for the year 2001. Adjustments were made with the Health Cost and Utilization Project's Nationwide Inpatient Sample and with data from private insurers. An estimated 33% of people reported with HIV disease did not receive HIV primary medical care. The estimate of unmet need for people with HIV (non-AIDS) was greater (51%) than for people living with AIDS (19%). In the Atlanta study, findings were limited because of the inability of HARS to track migration and the difficulty with missing data elements from source data sets that challenged deduplication of client-level data. All studies have the same goal: to more effectively describe unmet need for HIV primary care services in a way that is accessible to service and policy planners and have the ability to be replicated by communities across the United States.[4]

In our study, we continued the development of comprehensive data sources as indicators of HIV primary care utilization by expanding the time period of review to 5 years and by integrating several data sources at client level to create a more inclusive understanding of HIV primary care utilization. We proposed the following research questions: (1) Among people who have been diagnosed with HIV or AIDS and are living in the St Louis region, how many are utilizing medical care to treat their HIV? (2) What differences exist between those who are and those who are not receiving HIV primary care? (3) How do people who have been diagnosed with HIV or AIDS interact with the health system?

METHODS

Study Sample

This study integrated health utilization data from several different sources in Missouri with HARS to understand HIV primary care access. The sources were the AIDS Drug Assistance Program, Ryan White CARE Act Title Programs I and III, Sexually Transmitted Diseases Management Information System, Tuberculosis Database, and State of Missouri's Correctional Medical Services.

Analyses focused on people who were diagnosed with HIV or AIDS in the Missouri portion of the St Louis Eligible Metropolitan Area through 2002. The region is comprised of St Louis City and the following Missouri counties: St Louis County, St Charles County, Franklin County, Jefferson County, Lincoln County, and Warren County. Although Missouri has a law that allows anonymous HIV disease reporting,[7] anonymous case reports were excluded from this study because these data do not provide a means for linking client-level information across databases. Using these criteria, our sample consisted of data for 6555 individuals. Demographic data on these individuals are presented in Table 1.

Procedures

Study researchers encouraged the following database owners to contribute client-level data to the study: Missouri Department of Health and Senior Services (DHSS) programs (HIV, tuberculosis, sexually transmitted diseases [STDs]), St Louis City Health Department HIV program, Ryan White CARE Act Title I Services Planning Council staff, Ryan White CARE Act Title III staff, and the Missouri Department of Corrections. Database managers transferred to the HIV/AIDS Surveillance Unit of DHSS their available client-level utilization data related to HIV primary and general health services for the years 1992 through 2002. DHSS then integrated the data sets based on match of name, social security number, Medicaid number, and date of birth. After data integration, DHSS randomly assigned new unique identifiers and removed all other identifying information. This process protected client anonymity while it maintained the ability for subsequent analyses to focus on unique persons. DHSS then transferred the integrated and deidentified client-level database to the research team for coding and analysis with SPSS version 14.0 (SPSS Inc, Chicago, Ill).

Variables

Indicators of utilization of HIV primary care. The definition of being "in care" for HIV was to have evidence of utilization of HIV primary medical care during a 12-month period of time. This definition represents the standard for the measurement of the minimum level of care based on Ryan White CARE Act federal guidelines and was adopted by the St Louis HIV Services Planning Council.[8] Given the nature of the data that were integrated for this study, evidence of HIV care was defined as evidence of a CD4 or viral load test (e.g., the presence of a date or value for a lab test), evidence of HIV primary care service visits, or evidence of utilization of HIV-related medications from service authorization data. Missouri regulation (19 CSR 20–20.020) requires the dual reporting of CD4 and viral load tests. Reports for HIV cases and HIV-related diagnostic testing by laboratories and physicians have historically and consistently been validated at 95% completeness or higher.

TABLE 1—Study Sample Variables for HIV-Positive Individuals: St. Louis, Mo, 1998–2002

Variable	No.[a]	Percent or Mean (SD)
Gender	6549	
Man		84.9%
Woman		15.0%
Race/ethnicity	6531	
White		47.7%
African American		50.0%
Hispanic		1.1%
Asian		0.2%
Other/Unknown		1.0%
Exposure category	6554	
MSM		65.3%
MSM and IDU		5.2%
IDU		7.2%
Heterosexual sex		14.2%
Other[b]		8.1%
Age at HIV diagnosis	6206	33.1 (10.5)
Ever diagnosed with AIDS	6555	64.6%
AIDS diagnosis coincident with HIV diagnosis	4235	34.9%
Diagnosis year	6554	
1982 to 1987		3.3%
1988 to 1992		38.1%
1993 to 1997		35.8%
1998 to 2002		22.8%

Notes. MSM = men who have sex with men; IDU = injection drug use.

[a] Sample sizes are different over the years of study because the sample of persons living with HIV disease is not static over time.

[b] Exposed to HIV through other means such as blood products or confirmed other.

Table 2 displays the complete list of indicators selected to measure HIV primary care utilization. We coded evidence of utilization of HIV primary care into 7 dependent variables for 3 time periods: (1) evidence of care for any given year between 1998 and 2002, (2) evidence of care for each year between 1998 and 2002, and (3) evidence of care in the first year after a diagnosis of HIV.

Indicators of other health care utilization. We also coded indicators of utilization of other, non–HIV-specific health services to examine the association between HIV primary care and other health systems that are not necessarily focused on HIV-related medical care. Specific indicators for other health care utilization are outlined in Table 2 and include services for STDs, mental health care, and general health services. These variables were coded for the same time periods as HIV-specific primary care.

Client demographic variables. We also computed several demographic and descriptive variables from the HARS database, including age at HIV diagnosis. Race/ethnicity was coded as White or African American because of the small number of individuals who were not in 1 of those categories. Because gender is confounded with Centers for Disease Control and Prevention–defined HIV-exposure category, we coded a combined gender and HIV-exposure variable: men who reported sex with other men (MSM), MSM who also injected drugs, men exposed through injection drugs, women exposed through injection drugs, men exposed through heterosexual sex, women exposed through heterosexual sex, men exposed through other means such as blood products or confirmed other, and women exposed through other means such as blood products or confirmed other. In addition, we coded whether a person had received an AIDS diagnosis that preceded or was concurrent with the analysis in question. Where applicable, we coded date of death as reported in the HARS database. We also computed experience with the state corrections system and the STD program.

TABLE 2—Indicators of Health Care Utilization Among Sample of HIV-Positive Individuals: St Louis, Mo, 1998–2002

HIV Primary Care	General and Ancillary HIV Care
Evidence of CD4 or viral load test	Evidence of STD diagnosis or system contact
Diagnosis of opportunistic infection reported to HARS	Evidence of general health care services: dental services, durable medical equipment, health diagnoses, home health services, hospitalizations, immunizations, medical supplies, mental health services, physical therapy, ophthalmology, serologies, and x-rays
Evidence of utilization of primary medical care for HIV: insurance, laboratory, medication, medical visits, outpatient, lifeline (emergency medical services for home-bound patients), and neurological consultation	Evidence of ancillary HIV health care services: acupuncture, alternative therapy, massage, transportation, and chiropractic care
AIDS Drug Assistance Program utilization	Evidence of TB diagnosis or system contact

Notes. STD = sexually transmitted disease; HARS = HIV and AIDS Reporting System; TB = tuberculosis.

Data Analyses

We first conducted descriptive analyses of health care utilization for each of the 7 dependent time variables. For analyses of annual utilization, samples were comprised of people who tested positive for HIV and who were alive or who died during the year in question. People who died prior to the year of analysis were excluded. For the 5-year sample, people were included if they tested positive for HIV or AIDS through 1998 and were alive in 2002 (i.e., HIV-positive and alive during the entire period). We also analyzed health care utilization during the first year after a diagnosis of HIV or AIDS. This analysis excluded people who died prior to 1993, the year that a significant increase in funding for medical services was received through the Ryan White CARE Act.

After descriptive analyses, multivariate relationships were examined with logistic or linear regression with predictor variables entered in blocks of theoretically similar variables (demographics, indicators of health and wellness, and indicators of health utilization). All statistical tests were considered significant if they had a P value of .05 or less.

The study protocol was judged to be exempt from full review by the institutional review boards of the Missouri DHSS and the University of Missouri Health Sciences Center, because the study involved the use of deidentified secondary health utilization data.

RESULTS

Indicators of Utilization of Care

The percentage of people with evidence of having received HIV primary care ranged from 43% to 53.3% between 1998 and 2002. In 2002, the most recent year available for analysis, less than half (44.8%; n=4606) of those living with HIV or AIDS showed evidence of having utilized HIV primary care. Utilization of HIV primary care in prior years was as follows: 2001, 43.0% (n=4351); 2000, 53.3% (n=4136); 1999, 52.9% (n=3929); and 1998, 48.7% (n=3676). A reported CD4 or viral load value was evidence of HIV primary care utilization for the majority of those with evidence of HIV primary care in 2002.

To understand patterns of utilization of HIV primary care over time, we examined utilization across the full 5-year period between 1998 and 2002. Among this group, less than 20% (19.4%) had evidence of care for each year, and 29.5% had no evidence of care for the entire 5-year period. Seventy percent (70.5%) of the 5-year sample utilized primary care at least once during this period. Our findings suggest that most people living with HIV or AIDS are not meeting the minimum definition of being in care for HIV (evidence of care at least once per year). A majority of people in this sample (60.8%) had evidence of HIV primary care in the first year after their HIV diagnosis, however. This pattern was especially true for those who received their HIV diagnosis in 1997 or later, with more than three fourths having utilized care (76.9%).

Differences Between Those With and Without Evidence of Care

For most analyses, Whites were more likely overall than African Americans to show evidence of utilization of HIV primary care (see Table 3). One explanation is that Whites were also more likely than African Americans to have an AIDS diagnosis in each year (56.3% vs 50.5%, respectively, in 2002; $\chi^2=15.08$; $P<.05$). (The same pattern was true for every year from 1998 to 2002. We have presented a formal statistical test for 1 year to save space.) An examination of the relationship between HIV exposure category and utilization of care showed only 1 consistent pattern across time—women exposed to HIV through heterosexual sex were more likely to show evidence of HIV primary care utilization than were individuals in any other exposure category. Further, an AIDS diagnosis was found to be a predictor in all exposure groups of HIV primary care utilization. This was true for every year of examination and for the overall 5-year period (1998–2002). People with an AIDS diagnosis during or prior to 2002 were nearly 5 times more likely to have utilized HIV primary care between 1998 and 2002.

To examine factors associated with receipt of HIV primary care in the first year after an HIV diagnosis, we selected a sample of individuals who were diagnosed in 1997 or later. This time period was chosen as the cutoff because antiretroviral therapy was made generally available in publicly and privately funded health systems at this approximate time. An analysis of HIV primary care utilization in the first year after an HIV diagnosis showed that Whites were more likely to have evidence of care than were African Americans. This finding is important because an AIDS diagnosis was strongly associated with evidence of HIV primary care in that first year. Table 4 shows the percentage of people with an AIDS diagnosis in the first year after an HIV diagnosis by exposure category. For those diagnosed after 1997, 25.2% had an AIDS diagnosis within 90 days of testing

TABLE 3—Demographic Variables of HIV-Positive Persons With Evidence of Utilization of HIV-Specific Primary Care, by Year: St Louis, Mo, 1998–2002

	No. (%) With Evidence of HIV Primary Care					
Variable	1998	1999	2000	2001	2002	First Year After HIV Diagnosis
Overall	3676 (48.7)	3929 (52.9)	4136 (53.3)	4351 (43.0)[a]	4606 (44.8)	6277 (60.3)
Gender						
Man	3149 (47.7)	3349 (52.4)	3496 (52.4)	3653 (42.5)	3837 (44.2)	5304 (59.1)
Woman	523 (54.5)	576 (55.9)	635 (57.8)	693 (45.3)	764 (48.0)	967 (67.0)
Race/ethnicity						
White	1749 (52.1)	1843 (56.2)	1908 (55.7)	1975 (40.7)	2055 (45.1)	2939 (63.9)
African American	1847 (45.9)	2003 (50.1)	2141 (51.2)	2282 (45.1)	2444 (44.8)	3195 (57.2)
Hispanic	38 (42.1)	38 (50.0)	37 (48.6)	42 (35.7)	49 (36.7)	67 (64.2)
Exposure category						
MSM	2489 (49.1)	2620 (54.3)	2710 (54.3)	2784 (43.9)	2882 (46.1)	4073 (59.9)
MSM and IDU	228 (53.9)	232 (57.8)	228 (54.8)	224 (47.8)	223 (47.1)	312 (55.8)
IDU	315 (46.3)	321 (49.5)	322 (48.1)	323 (45.8)	326 (45.1)	453 (57.0)
Heterosexual sex	435 (54.3)	496 (60.3)	579 (63.9)	674 (46.1)	753 (50.6)	918 (63.2)

Notes. MSM = men who have sex with men; IDU = injection drug use.

[a] There was an observed drop in reported CD4 and viral load values between 2000 and 2001. It is not yet clear why this drop occurred.

TABLE 4—Number and Percentage of Persons With AIDS Diagnosis in the First Year After HIV Diagnosis by Exposure Category: St Louis, Mo, 1998–2002

	MSM	MSM and IDU	Man IDU	Women IDU	Het Man	Het Woman	Man Other[a]	Woman Other[a]
Diagnosed Before 1997	3077 (37)	269 (30)	224 (25)	130 (31)	102 (28)	338 (27)	90 (30)	46 (15)
Diagnosed After 1997	996 (38)	43 (40)	58 (43)	40 (45)	187 (35)	291 (27)	198 (16)	105 (6)

Notes. MSM = men who have sex with men; IDU = injection drug use; Het = heterosexual sex. The Centers for Disease Control and Prevention's definition of AIDS was expanded in 1993, a change that could impact the percentage of people with and without an AIDS diagnosis before or after 1997.

[a] Exposed to HIV through other means such as blood products or confirmed other.

positive for HIV. After we controlled for race, age, and other exposure categories, MSM were 5 times more likely than were other groups to have evidence of care in the first year. By contrast, women exposed through injection drug use were about half as likely as other groups to show evidence of care in the first year. Further, even though the earlier cross-sectional analyses found that women exposed through heterosexual sex utilized HIV primary care at somewhat higher rates than did other groups in any given year, these women were about half as likely as people in other exposure categories to show evidence of HIV primary care in the first year after diagnosis.

Interaction With the Health System

We also examined the impact of the receipt of non–HIV-specific health care services on HIV primary care. Our analyses focused on 4 classes of services: (1) services from an STD program, (2) Ryan White CARE Act Title I ancillary HIV services (e.g., mental health, alternative therapies); (3) Ryan White CARE Act Title I general health care services (e.g., dental services, durable medical equipment, health diagnoses, home health services, non–HIV-related hospitalizations, immunizations, medical supplies, mental health services, physical therapy, ophthalmology, serologies, x-rays), and (4) Ryan White CARE Act Title III general health care services (e.g., x-rays, immunizations). Our analyses showed that all 4 categories of services were strongly associated with evidence of HIV primary care. For example, individuals who received STD services ranged from 2 to 6 times more likely to have evidence of HIV primary care than people without STD services, dependent upon the year of analysis. Although ancillary HIV services were not associated with evidence of HIV primary care in each year of analysis, people who received ancillary HIV services between 1998 and 2002 had evidence of HIV primary care for more years during that period than people who did not receive ancillary HIV services. Further, people who received ancillary HIV services in the first year after they received their HIV diagnosis were nearly 5 times more likely to show evidence of HIV primary care in that first year than people who did not receive ancillary HIV services. This finding reflects those in similar studies of ancillary HIV services and their impact on HIV primary care.[9,11–13] Similar patterns were observed for general health care services, particularly those provided under Ryan White CARE Act Title III.

DISCUSSION

These results suggest that people generally utilize HIV primary care soon after an HIV diagnosis, but that they may do so largely because they are sick. There is some variation by exposure category and demographics in terms of utilization of HIV primary care; however, there is a lot less variation for those who have an AIDS diagnosis in the first year after HIV diagnosis.

Although people with HIV utilize HIV primary care and are generally sick when they do so, in the longer term (5-year period), utilization of HIV primary care is inconsistent by most. The finding that people with HIV utilize HIV primary care inconsistently after initial utilization has been observed elsewhere[4,10] and suggests there may be a more fluid understanding of utilization of HIV primary care among people living with HIV—one where people are not distinctly in or out of HIV primary care but have a relationship with the primary care system that is not easily defined by periods of time or policy expectation. This inconsistency of utilization suggests that a current distinction between those (during the period of 1998 through 2002) who are "not in care" and those who need help utilizing and maintaining utilization of HIV primary care is perhaps false. In essence, being "in care" and "out of care" may not be as distinct as is posited in policy.

There may be several explanations for inconsistent utilization of primary care. For example, although the public health system appears to link people effectively from HIV diagnosis to initial HIV primary care utilization, the HIV primary care system does not ensure consistent utilization of care. A second explanation may involve the understanding of adequate care utilization by people themselves. The policy of the primary care system may state a minimum expectation of HIV primary care utilization annually; however, people themselves may feel otherwise and may utilize HIV primary care based on other factors such as symptoms and perceived wellbeing. The observation that AIDS was the central predictor of utilization of HIV primary care supports this explanation; studies that seek to understand the social construction of HIV primary care utilization in terms of care adequacy and reasoning for seeking care will be an important contribution to public health policy and planning.

Recent Ryan White CARE Act policies to encourage HIV primary care utilization through adjunct programs such as general health care and ancillary HIV care appear to be successful, because people who had evidence of Ryan White CARE Act HIV primary care also utilized ancillary Ryan White CARE Act programs. This was only observable for those data that could be compared at the client level: Title I and Title III data. Our findings echo what has been observed elsewhere: that people who receive ancillary HIV services funded by the Ryan White CARE Act are more likely to utilize HIV primary care than are those who do not receive ancillary HIV services.[9,11–13] Although our analyses do not indicate whether involvement in ancillary HIV services was before, after, or coincident with entry into HIV primary care, the co-occurrence of these services suggests that ancillary HIV services play an important role in access to or maintenance in HIV primary care. Further, although it is true that this relationship is somewhat confounded by the fact that access to a few ancillary HIV services is through an HIV primary care physician, most of the ancillary HIV services funded by Titles I and III in Missouri are accessed through a case manager and not a physician.

This project takes an important step toward the integration of disparate information systems to tell a more comprehensive story about HIV primary care utilization over a 5-year period of time. The combination of laboratory values and program data allowed the evaluation of indicators of utilization for future planning purposes. The CD4 and viral load values were by far the best indicators of HIV primary care utilization, and there were few instances when Ryan White CARE Act primary care program data were not accompanied by lab values during a calendar year period.

Limitations

Although CD4 and viral load values were observed to be the strongest indicators of HIV primary care utilization, health program data at the client level are important in evaluating specific program utilization and care system transition. Because Ryan White CARE Act programs do not provide the majority of primary care for HIV, it is necessary to evaluate overall utilization of primary care throughout the various systems of HIV primary health care. This requires access to health program data such as Medicaid, Medicare, Veterans Administration, and hospital discharge. Private-payer utilization data will be even more challenging to obtain.

Although this project integrated data never before analyzed at the client level over a 5-year period, the information addressed was not a complete picture of care in Missouri. The basis for the data set was HARS, which contains data for people diagnosed in Missouri. People living in Missouri who were diagnosed elsewhere were not included in these data. Although a recent national study found that 5.4% of people diagnosed with AIDS migrate from the state where they were diagnosed to another state where they die,[14] the reported migration rate may only be useful for estimating completeness relative to AIDS migration versus HIV (non-AIDS) migration. Further, the absence of evidence of care in the data set reviewed is not sufficient to state that someone is not utilizing HIV primary care, because health program information was limited. As has been noted elsewhere, studies like this give a "least-common denominator" view of care utilization.[4]

Conclusions

Our findings demonstrated that client-level data integration with disparate sources of health utilization data and HARS data can contribute to a greater understanding of unmet need for HIV primary care over a period of years. Although the different health utilization databases made it a challenge to identify common indicators of care, data integration is possible. Further, CD4 and viral load values appear to be efficient indicators of HIV primary care utilization in St Louis, Mo, at least when compared with health utilization data from Ryan White CARE Act Title Programs I and III, AIDS Drug Assistance Program, and Missouri Department of Corrections' health database. We recommend that future studies expand the health care utilization data input so that viral load and CD4 reporting values can be examined for their contribution as indicators of HIV primary care utilization. This is important because needed public health resources could be used efficiently if evaluations of health care utilization were guided by a proven set of HIV primary health care utilization indicators. ■

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Contributors

B.E. Meyerson originated and conducted the study, and led the writing of the article. W.D. Klinkenberg managed the data analysis. D.R. Perkins assisted with the data analysis. B.T. Laffoon created the integrated database. All authors contributed to the writing of the article.

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Human Participant Protection

The study protocol was judged to be exempt from full review by the institutional review boards of the Missouri Department of Health and Senior Services and the University of Missouri Health Sciences Center because the study involved the use of deidentified secondary health utilization data.

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